



ERN ReCONNET Newsletter

Issue n. 15
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Welcome to the new members of ERN ReCONNET



As the last step of the [2019 call for membership to the existing European Reference Networks](#), the ERN Board of Member States, as given in the Implementing Decision 2014/287/EU Article 10, approved on 26 November 2021 by consensus 620 applicants.

The newly approved members joined the ERNs on the 1st January 2022.

ERN ReCONNET is very glad to welcome the **30 new members** of the network. We truly believe that this is a crucial milestone for our ERN.

The first step on this path has been a preparatory webinar for the new members held on 17th January.



Members of ERN ReCONNET

ERN Exchange Programme to restart in March



Due to the fourth wave of the Covid-19 pandemic and the steep rise in infection rates, an increasing number of exchange visits have had to be cancelled or postponed. Therefore, in close consultation with the European Commission (HaDEA and DG SANTE), **the implementation of the Exchange Programme has been suspended** until the situation improves.

The Contractor expects to be able to resume the Programme activities from 1. March 2022 onwards – this will be reviewed and confirmed with the European Commission based on the outlook in February.

[More info](#)

ERN ReCONNET document on vaccination and rCTDs patients



ERN ReCONNET published on its website the article "**New rapidly evolving challenges on the management and vaccination of rare and complex connective tissue and musculoskeletal diseases patients in the COVID-19 era: points of view of the ERN ReCONNET**".

The **COVID-19** pandemic has led to increasing challenges for both patients and health care professionals managing patients affected by rare and complex Connective Tissue Diseases (rCTDs). They include limited access of patients to

specialized health care with difficulties in early diagnosis and or routine follow-up, the risk of contracting severe SARS-CoV2-infections in this population, and the need for balancing the infectious risk under immunosuppressive treatment against the risk of uncontrolled disease activity. Since the first wave of the COVID-19 pandemic in Spring 2020, rCTDs patients were faced with multiple unforeseen issues related to COVID-19, particularly vulnerability to severe SARS-CoV2 infections under continued DMARD therapies, uncertainty about special hygiene measures and reliability of test results, and difficulties to contact their treating physicians, often resulting in frustration due to lack of information or even anxiety or depression. In addition, clinicians had to face the complexity of treating rCTDs patients with active disease who required rapid therapeutic decisions despite the risk of being immunocompromised in the middle of a pandemic. Moreover, after the COVID-19 vaccination campaign started in Europe, other burning questions for rCTDs patients concerning the effectiveness of COVID-19 vaccination have raised.

The example provided by the ERN ReCONNET shows that thanks to the involvement of the leading experts on rCTDs and the main stakeholders, crucial issues raised during the pandemic can be addressed and a common approach to the management of rCTDs can be defined while providing the community of rCTDs patients with the much-needed information derived from the evidence and the sharing of the clinical and patient experiences of the Network.

[Read the document](#)

ERN ReCONNET Board of Network



The ERN ReCONNET **Board of Network** took place on 21st December 2021. It was a great occasion to discuss on several topics: the new ERN ReCONNET Members and ePAGs, the disease expansion protocol, the evaluation of HCPs and ERN National Hubs, the Vaccinate study, the Supplement "Rare inside Rare", and the next ERN ReCONNET Plenary Meeting.

Next ERN ReCONNET Plenary Meeting

Due to the pandemic, the next ERN ReCONNET Plenary Meeting will be held **online** on 3rd and 4th February 2022.

EJP RD Funding Opportunities



Joint Transnational Call 2022

The **EJP RD Joint Transnational Call 2022** for Rare Diseases Research Project (JTC 2022) focuses on the “Development of new analytic tools and pathways to accelerate diagnosis and facilitate diagnostic monitoring of rare diseases”. The aim of the call is to enable scientists in different countries to build an effective collaboration on a common interdisciplinary research project based on complementarities and sharing of expertise, with expected impact to use the results in the future for benefit of patients. There will be a two-stage submission procedure for joint applications: pre-proposals and full proposals. First deadline is on **16/02/2022**.

[More info](#)



Networking Support Scheme

The **first aim** of the **Networking Support Scheme** is to encourage sharing of knowledge on rare diseases or rare cancers between health care professionals, researchers and patients in new or expanding research networks by funding networking events. The **second aim** of the **Networking Support Scheme** is to enable or increase the participation of usually underrepresented countries in Europe in new and in expanding research networks on rare diseases or rare cancers. Applicants can choose between the format of a **face-to-face meeting**, an **online meeting** or a **hybrid meeting** if networking is secured. Next deadline **1/03/2022 at 14.00 (CET)**

[More info](#)

Italian ERNs online event

Points consider to the rare diseases community



ERN ReCONNET, [MetabERN](#), [ERN BOND](#), the Federation of Associations of People with Rare Diseases in Italy ([Uniamo FIMR Onlus](#)), the Italian National Institute of Health ([Istituto Superiore di Sanità](#)) and [ePAG Italia](#) organised an online event on **30th November 2021** from **4pm** to **6pm** CET, which was attended by more than 150 rare disease coordinators of Italian regions, patients' associations, hospital managers, health directors/chief medical officers, Rare Disease Registry and rare disease centres managers, political representatives, pharmaceutical industries, general practitioners, etc.

A document summarising the discussion will be published on the ERN ReCONNET website.

[More info](#)

Ongoing projects

In order to assess their educational needs, ERN ReCONNET developed **two online surveys** for healthcare professionals and for patients and caregivers living with rCTDs.

The survey for clinicians was developed thanks to the support of our Task Force on Education for healthcare professionals. The survey for patients and caregivers was co-designed with the precious support of the ePAGs

Representatives that have also contributed to the translations in 15 European languages.

Thanks to the everyone's' commitment in sharing and disseminating the surveys in the different communities, the final numbers of replies are **1426** for patients and caregivers and **59** for HCPs.

For the **ERN ReCONNET Study** on COVID-19 Vaccination in Rare and Complex Connective Tissue Diseases **VACCINATE** there will be an interim analysis of the data collected in the first 6 months of follow-up (data lock on 17th January 2022).

The ERN ReCONNET **EDS Expert Panel Consensus Meeting on Patient's Pathways** took place on 17th December 2021. Thanks to the precious contribution of all participants to the work on patients' care pathways in EDS and the collaboration with the EDS Society, it was a really interactive discussion that marked a new milestone for all EDS patients. We will update soon on the next steps.

New sections on ERN ReCONNET website



On "**Activities**" label you will find new sections: **Documents**, **Exchange programme** and more resources on **CPMS**, including the downloadable guides, available in several languages.

Website

Past webinars



Find out the ERN ReCONNET webinars: they are available on our website and on our YouTube channel.

Past webinars

Clinical Patient Management System



The **Clinical Patient Management System** (CPMS) aims at supporting ERNs in improving the diagnosis and treatment of rare or low prevalence complex diseases across national borders of Member States in Europe.

The CPMS is a secure **Software as a Service** (SaaS) that enables health professionals to enrol patients using comprehensive data models. Health professionals can use the CPMS to collaborate actively and share patient within and across ERNs.

For more information on how to access the CPMS and how to request a virtual consultation, please contact us at:

helpdesk.reconnet@ao-pisa.toscana.it

More info

CPMS National Hubs



The ERN ReCONNET **CPMS National Hubs** serve as national contact point to support the usage and the dissemination of the CPMS at national/local level, and as national reference contact for specialists, general practitioners and other healthcare professionals in each country in order to provide information on the functioning of the platform.

The National Hub also contribute to connecting even the more remoter healthcare providers and patients to highly specialised services of the ERN ReCONNET.

The ERN ReCONNET National Hubs developed the translation of the **CPMS guides** into French, German, Dutch, Italian, Portuguese and Romanian, available at this [link](#).

[More info](#)

ERN ReCONNET IT Services



You can find all information about the **ERN ReCONNET IT Services** on the ERN ReCONNET website, with additional **CPMS training videos**.

[More info](#)

SOCIAL MEDIA CHANNELS



ERN ReCONNET YouTube Channel and Twitter page

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ERN ReCONNET is one of the 24 European Reference Networks (ERNs) approved by the ERN Board of Member States. The ERNs are supported by the European Commission. For more information about the ERNs and the EU health strategy please visit ec.europa.eu/health/ern_en



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